

Improving Pediatric Cancer Survivorship Care through SurvivorLink

Principal Investigator:	Mertens, Ann, Ph.D.
Organization:	Emory University
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Summary: As the number of cancer survivors increases, the need to educate primary care providers about the unique needs and care of these individuals has become more urgent. This is particularly true for childhood cancer survivors for whom cancer therapies, with overall cure rates of 75 to 80 percent, are highly successful. Yet high-quality individualized survivorship care is challenging due to: 1) multiple transitions in care among primary and specialty care providers; and 2) the lack of knowledge about survivor issues among providers, patients, and their families.

Dr. Mertens and her research team addressed these challenges by building the SurvivorLink system, a personal health record with the goals to improve pediatric cancer survivors' transition to pediatric primary and specialty care, and increase patient, family, and provider knowledge about survivor issues. SurvivorLink is designed to store personal health documents, primarily the Survivor Healthcare Plan which includes a cancer treatment summary, individualized risk- and late-effects screening profiles, and other clinical information needed to provide high-quality long-term care to survivors. SurvivorLink also provides educational materials that improve awareness of survivorship issues and best practices in survivor care, including continuing medical education (CME) credits to providers who complete educational materials using the SurvivorLink Web site.

SurvivorLink had three target user groups: patients and their families; providers; and researchers. Participants for this pilot study were recruited through the five cancer treatment centers in the State of Georgia, as well as Georgia Comprehensive Cancer Registry records. The impact of SurvivorLink was evaluated by measuring outcomes related to both SurvivorLink utilization and the effects that utilization had on aspects of survivor care, including patient and provider awareness of survivor issues and percentage of patients receiving recommended survivorship care.

Specific Aims:

- Collect data on pediatric cancer survivors in SurvivorLink. **(Achieved)**
- Facilitate the exchange of clinical information at key transitions. **(Achieved)**
- Provide patients with easy access to individualized educational materials and evidence-based late-effects screening recommendations. **(Achieved)**
- Provide researchers with longitudinal information on incidence of late effects in pediatric cancer

survivors. (Achieved)

2012 Activities: Recruitment for SurvivorLink was a major focus of the year. The research team employed several methods to recruit patients, including contacting individuals in the Georgia Comprehensive Cancer Registry, collaborating with local pediatric cancer clinics, and promoting SurvivorLink through social media. The research team partnered with two cancer advocacy organizations, CURE and Camp Sunshine, to provide information about SurvivorLink at workshops, conferences, and other survivorship events.

To allow additional time for patient recruitment, Dr. Mertens used a 1-year no-cost extension. As last reported in the AHRQ Research Reporting System, project progress was on track, and budget spending was on target. This project was completed in February 2012.

Impact and Findings: The project team conducted focus groups and semi-structured interviews with providers, patients, and parents to understand the needs of these groups. The focus groups indicated that providers wanted a system that allows efficient access to patient health information before the patient visit. Patients and their parents expressed concern about privacy, particularly from insurance companies, colleges, and employers. Additionally, the study staff learned from the focus groups that most parents were not familiar with the importance of survivor care.

Based on the focus group findings, the patient-parent portal was designed with special attention to security and privacy. Similar to a social networking site, patients and parents can invite their primary care doctor and other physicians to access their survivor health plan online to facilitate information exchange, and may un-invite them at any time. As an added security measure, patients and parents are able to monitor who has access to their information. When patients or parents sign up, their survivor health care plan is uploaded into the system, and are able to give permission for their providers to post information as well. The portal highlights tailored information for individual patients based on their risks. Patients and parents are also able to link current medications with relevant health links, and are able to store other information as scanable documents.

To maximize its recruiting efforts, the research team analyzed recruitment numbers for each recruitment method. Of the 218 pediatric cancer patients contacted through Children's Healthcare of Atlanta, 23 (11 percent) registered with SurvivorLink after mail contact, and 49 (22 percent) after mail contact and a telephone call. Of these patients, individuals who previously attended a cancer survivorship clinic were significantly more likely to register with SurvivorLink than those who had not attended a survivorship clinic. At the community outreach survivorship events, 22 percent of patients or parents who engaged with SurvivorLink staff registered with the Web site. Additionally, following outreach events, the average number of weekly visits to SurvivorLink increased by 25. In the first 4 months of a Facebook social media campaign, the SurvivorLink Facebook page received 645 views and 58 "likes."

As of the end of the study, 364 people registered with SurvivorLink. Of these, 132 were providers, 131 were parents, and 53 were patients. There have been 4,001 visits to the SurvivorLink Web site. The average number of pages viewed was 5.84, and the average length of time on the site was 6.98 minutes. Fertility and neurocognitive issues were among the most frequently searched types of information. Among providers who have visited SurvivorLink, 50 continuing medical education credits have been completed. In addition, SurvivorLink continues to be offered to patients attending the Cancer Survivor Programs and through cancer advocacy partner organizations. Funds have been procured to sustain this [Web site](#).

Target Population: Cancer, Pediatric*, Teenagers

Strategic Goal: Develop and disseminate health IT evidence and evidence-based tools to support patient-centered care, the coordination of care across transitions, and the electronic exchange of health information to improve quality of care.

Business Goal: Implementation and Use

** This target population is one of AHRQ's priority populations.*